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A Social Skills Support Program For Children With Down Syndrome And Their Typically Developing Siblings: Effect On Sibling Relationship

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SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

Abstract

Children with Down syndrome (DS) demonstrate differences in social and communication skills resulting in atypical relationships with others, including siblings. Typically-developing (TD) siblings face their own social and emotional adjustment needs that impact the sibling relationship. The current study examined the effects of a 10-week social skills support program on the sibling relationship between children with DS and their TD siblings. Two sibling dyads completed the program consisting of skills instruction for children with DS, a support group for TD siblings, and cooperative recreation activities for all children together. The sibling relationship was measured through self-report questionnaires and direct observations of sibling interactions. Results show preliminary evidence that a social skills support group may help improve the sibling relationship and suggests the need for further investigation. TD siblings are a critical lifelong support for individuals with DS and these results can help improve quality of life for the entire family system.

Keywords

Down syndrome, typically-developing sibling, sibling relationship, support group, social skills, applied behavioural analysis.

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Introduction

Sibling relationships are one of the strongest relationships that humans develop (Brody, 2004). The relationship that one has with their sibling plays a crucial role in shaping one's childhood, adolescence, and adulthood and influences all areas of social and emotional functioning (Floyd, Purcell, Richardson, & Kupersmidt, 2009; Noller, 2005; Milevsky & Heerwagen, 2013). Additionally, family systems theory asserts that the relationship between two siblings can impact all other relationships within the family unit (Minuchin, 1974; Seltzer, Begun, Seltzer, & Krauss, 1991). The quality of the sibling relationship is characterised by how siblings interact and engage with one another and contains positive and negative dimensions, including warmth/closeness, conflict, rivalry, and relative status/power (Furman & Buhrmester, 1985; Allison & Campbell, 2015). Studies show that children in sibling relationships characterized as high in warmth and low in conflict develop fewer internalising symptoms such as anxiety and depression (Buist, Deković, & Prinzie, 2013). Alternatively, sibling relationships that are low in warmth and high in conflict can result in increased incidence of externalizing symptoms such as aggression, delinquency, and antisocial behaviour (Bank, Burraston, & Snyder, 2004; Buist et al., 2014; Slomkowski, Rende, Conger, Simons, & Conger, 2001). While a large body of literature exists investigating typically-developing (TD) sibling relationships, only recently has research started to examine whether, and how, the sibling relationship is affected by the presence of a developmental disability. There is even less literature evaluating the sibling relationship specifically when Down Syndrome (DS) is present.

DS is a chromosomal disorder that is caused by the presence of an extra chromosome 21. It is one of the most common congenital anomalies worldwide, with approximately 1 in 750 live-born babies in Canada having DS each year (Public Health Agency of Canada, 2017).

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Individuals with DS are at an increased risk for several medical conditions and experience developmental and intellectual delays. Children with DS can show some problems with social behaviour and communication skills that may influence the sibling relationship negatively, such as trouble controlling impulses, trouble with interaction and play skills, and trouble managing frustration (Choi & Van Riper, 2013; Hodapp and Urbano, 2007; Sigman et al., 1999). However, children with Down syndrome also show unique behaviors that may positively influence the sibling relationship, such as increased sociability and a desire to seek out interactions with others (Jahromi et al. 2008; Pollard, Barry, Freedman, & Kotchick, 2013). Just as with TD siblings, the sibling relationship between children with DS and their TD siblings can impact all aspects of development and family life (Floyd et al., 2009; Noller, 2005; Milevsky & Heerwagen, 2013; Minuchin, 1974; Seltzer et al., 1991). The sibling relationship is also important as individuals with DS live longer and rely more on their TD sibling(s) for care later in life (Dew, Llewellyn, Baladin, 2004; Orsmond & Seltzer, 2007). Overall, the literature suggests that it would be worthwhile to develop and implement interventions designed to improve the quality of the sibling relationship. The current study was designed to evaluate the effects of a social skills support program for children with DS and their typically-developing (TD) siblings on the quality of the sibling relationship.

Down Syndrome and the Sibling Relationship

The literature investigating how the quality of the sibling relationship is impacted by the presence of a general developmental disability demonstrate mixed results. Some studies show that the sibling relationship is affected positively, with more warmth and less conflict (Roper, Alfred, Mandleco, Freeborn, & Dyches, 2014; Stoneman, 2005). Contrarily, some studies show that it is affected negatively, with less warmth, higher conflict, less interaction, and less prosocial

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behaviour (Allison & Campbell, 2015; Fisman, Wolf, Ellison, & Freeman, 2000). While this research is useful, one of the limitations in the above-mentioned studies is the grouping of multiple disability groups in the samples. Cuskelly (1999) and Cuskelly and Gunn (2003) argue that sibling relationship research should be conducted on specific diagnostic groups separately, as using groups composed of multiple disability types does not allow effects particular to one group to be identified. In support of this, Seltzer, Greenberg, Orsmond, and Lounds (2005) published a review paper looking at research done on sibling relationships when one sibling had an intellectual disability and concluded that different disability types – especially DS and Autism Spectrum Disorder (ASD) which are often studied together- led to different outcomes in the sibling relationship and TD sibling's coping. Specifically, when one of the siblings has DS, the sibling relationship is characterized by more closeness, affection, nurturance, and admiration compared to the sibling relationship when one of the siblings has autism or another pervasive developmental disability (Hodapp & Dykens, 2012; Kaminsky & Dewey, 2001; Seltzer et al., 2005). This could be because a common aspect of the Down syndrome phenotype is increased sociability and a desire to seek out interactions with others (Jahromi et al. 2008; Pollard, Barry, Freedman, & Kotchick, 2013). Clearly, it is important to study if and how DS affects the sibling relationship separately from other disability groups, however, only a relatively small amount of research has done this.

The studies that have looked at the sibling relationship when one sibling is typically developing and the other specifically has a diagnosis of DS also show mixed results. Some results show that, compared to sibling relationships when both children are TD, the sibling relationship between children with DS and their TD siblings is positive with more characteristics of empathy and friendship (Pereira-Silva, Crolman, Almeida, & Rooke, 2017). One study did not

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show any differences in sibling relationship when one child has a diagnosis of DS compared to when both children are TD (Cuskelly & Gunn, 2003). Other studies show that there can be negative effects on the sibling relationship, in terms of more conflict and less frequent interactions (Hodapp and Urbano, 2007; Pollard et al., 2013). It is unknown why the literature shows mixed results, but a possible explanation includes differences in the way the sibling relationship was measured between studies. For example, it appears that the studies showing a positive effect on the relationship used parent self-report data to measure the sibling relationship, whereas studies reporting more negative effects used TD sibling self-report data. Regardless, it is clear that the sibling relationship can be affected by the presence of DS and, as the sibling relationship is important to both siblings' development and also family functioning, it is worthwhile to study ways to improve the sibling relationship.

Factors that Improve the Sibling Relationship

In designing targeted interventions to improve the sibling relationship specifically when one sibling has DS, we need to identify the factors that impact that relationship. Studies show that the sibling relationship is more positive when: 1) the individual with DS has good social and communication skills and 2) the TD sibling has strong emotional coping/adjustment skills (Choi & Van Riper, 2013; Cuskelly, 2016; Hodapp & Urbano, 2007; Pollard et al., 2013).

Interventions which target these two areas may have positive collateral effects on improving the sibling relationship.

Social and Communication Skills of the Individual with DS. As mentioned, individuals with DS are known to have problems with social behaviour and communication skills, such as trouble controlling impulses, trouble with interaction and play skills, and trouble managing frustration. Studies have shown that these concerns negatively affect the sibling

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relationship (Choi & Van Riper, 2013; Hodapp & Urbano, 2007; Sigman et al., 1999). For example, 284 TD adult siblings of individuals with DS completed *The Adult Sibling Relationship Questionnaire* online survey (Hodapp & Urbano; 2007). The questionnaire measured the number and length of contacts between siblings and their brothers/sisters with DS as well as the warmth, closeness, and positiveness of the sibling relationship. They correlated the scores on that questionnaire with reports of the brother/sister with DS's behaviour concerns and level of functioning. They found that closer, more positively rated sibling relationships were significantly associated with: 1) more frequent and lengthy interactions between siblings and 2) brothers/sisters with DS who had lower levels of behavioural/emotional problems and were better at social skills and maintaining friendships. Based on these findings, interventions to improve the sibling relationship would do well to include programs aimed at raising the social and communication skills of the child with DS.

Looking in the literature, several studies have successfully used Applied Behavior Analytic (ABA) techniques to improve the interaction and communication skills of children with DS including verbal imitation, responding to questions, emotional regulation, and spontaneous language (Bauer, Jones, & Feeley, 2014; Feeley, Jones, Blackburn, & Bauer, 2011). For example, Bauer et al. (2014) delivered ABA-based interventions to 2 children with DS aimed at increasing their ability to respond to questions, a skill that is important in reciprocal communication. A multiple-baseline probe design across 22 sessions was used to examine the effectiveness of multiple opportunities, prompting, reinforcement, and error correction procedures on the participants' responses. Correct responses to a question resulted in verbal praise and physical interaction, while incorrect responses or no response to a question resulted in an error correct procedure in which the interventionist said something like, 'Uh uh, try again',

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and immediately presented another opportunity by asking the question again. All of the children succeeded in acquiring the ability to respond appropriately to questions, generalized those responses to interactions with other adults not associated with the intervention sessions, and maintained responding to questions across a one-month period. More studies are needed to increase the sample size and generalizability, but the results show that ABA models of intervention can improve the social and communication skills of the child with DS.

Since we know that the sibling relationship is rated more positively when the child with DS has strong social and communication skills, ABA models of intervention to improve social and communication skills may be used to concurrently improve the sibling relationship. There are no studies showing exactly this in the DS literature, however, there is evidence from the ASD literature that such interventions do indeed lead to more positive interactions between siblings and improve the sibling relationship (Boyden, 2012; Greenwood, 2018; Kryzak & Jones, 2017). Examining this when the diagnosis is specifically DS is one of the goals of the current study.

Emotional Coping/Adjustment Skills of the TD Sibling. Traditionally, research around sibling relationships and the presence of DS has focused not on the sibling relationship, but on the psychosocial outcomes experienced by the TD sibling. Research findings have been varied as to whether having a sibling with a developmental disability is related to positive outcomes, such as greater self-control, increased empathy for others, and greater adaptive coping abilities, or negative outcomes, such as greater risk for conflict, increased rates of psychological disorders, and difficulties with social isolation, self-esteem, and adjustment (Barnett & Hunter, 2012; Dew, Balandin, & Llewellyn, 2008; Findler & Vardi 2009; Mandleco, Marshall, Olsen, & Dyches, 2003; Orsmond & Seltzer 2007). Regardless, it makes sense that if the TD sibling is experiencing poor emotional coping and adjustment from having a sibling with DS, there would

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be less warmth, closeness, and interaction between siblings. Indeed, this is precisely what the literature shows (Cuskelly, 2016; Pollard, Barry, Freedman, & Kotchick, 2013).

For example, Pollard et al. (2013) looked at sibling relationship quality in 38 TD siblings, ages 11-17, who had a brother or sister with DS. The participants completed the sibling domain of *The Network of Relationships Inventory*, which assessed features such as social support and negative interchanges within the sibling relationship to give an overall relationship quality score. Participants self-reported anxiety was assessed using *The Multidimensional Anxiety Scale for Children*. They found that anxiety in the TD sibling was significantly and negatively correlated with overall sibling relationship quality. Based on these findings, interventions to improve the sibling relationship would also do well to include programming aimed at improving the emotional coping and adjustment of the TD sibling.

Current literature shows that support group type programs have been successful in improving the emotional coping and adjustment of the TD sibling (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005; Kryzak, Cengher, & Fienup, 2015; Roberts et al., 2015; Roberts, Ejova, Giallo, Strohm, & Lillie, 2016). The TD sibling support groups typically involve regular meetings where a group of TD siblings learn about their brother's/sister's disability, discuss issues and emotions, build a support network, and learn about coping strategies. Two of the most well-known programs are SibShops, developed by Meyer and Vadasy (1994), and SibworkS, developed by Strohm (2010). In addition to improving TD sibling's adjustment, coping, and emotional well-being, some studies have even noticed a small but encouraging concurrent improvement in sibling relationship quality (Kryzak et al., 2015; Roberts et al., 2015).

As an example, Roberts et al. (2015) recruited 56 children, aged 7–12, who had a sibling with some form of developmental disability. The children were randomly assigned to either the

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SibworkS program ($n = 30$) or waitlist control ($n = 26$). The emotional and behavioural functioning of the children were measured both pre and post intervention using *The Strengths and Difficulties Questionnaire – Parent Version*. The questionnaire has five subscales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. Siblings participating in the SibworkS intervention were reported by their parents to have fewer emotional and behavioral difficulties than siblings in the control group immediately following the intervention and also at a 3-month follow-up.

Since we know that the sibling relationship is rated more positively when the TD child has strong emotional coping/adjustment skills, support group programming to facilitate development of those skills may be used to concurrently improve the sibling relationship. There is evidence that this is the case. Although it was not the main area of focus, Roberts et al. (2015) also included one parent-report measure of sibling relationship and found that the sibling relationship was reported as slightly better, specifically with less reported conflict, after TD sibling completed the support group. More studies are needed to corroborate this finding when the sibling specifically has DS, which is an aim of the current study.

Gaps in the Current Literature

There are several gaps in the presented literature that the current study will address. Given the information in the previous section, it is reasonable to posit that combining ABA based interventions to improve the social and communication skills of the child with DS with support group interventions to improve the emotional coping/adjustment of the TD sibling may have the most success at improving the sibling relationship. However, to the best available knowledge, no research has explicitly evaluated how combining interventions affects the sibling relationship in sibling dyads where one child has DS. However, there are such studies for

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children with ASD and their TD siblings (Choi & Van Riper, 2013; Kryzak, Cengher, & Fienup, 2015). A landmark study by Kryzak, Cengher, and Fienup (2015) examined the effects of a community support group providing intervention for both the children with ASD and their TD siblings at the same time. They reported on 14 sibling dyads, ages 4 to 14, who completed a 7-week program consisting of a support group for the TD siblings, using curricula based on the SibShop program developed by Meyer and Vadasy (1994), and individualised skills instruction for the children with ASD, using ABA interventions to address skills important for interacting with their siblings. Their results revealed increases in communicative initiations and responses for both siblings after completion of the program, pointing to an improvement in the sibling relationship. Some limitations to note are the use of only a single measure of sibling relationship and concerns about generalizability of the increased communication (i.e., did the effects also occur in environments outside the program?). Nonetheless, the Kryszak et al. (2015) study is very important and served as a starting model for the current study.

Importantly, the Kryszak et al. (2015) study was one of the first in the ASD sibling relationship literature to measure the sibling relationship using observable changes in behavior of the siblings toward each other (reciprocal initiations and responses and affect between siblings). Most of the research on sibling relationships specifically involving DS has relied on indirect self-report measures completed by the parents or the TD siblings. Self-report measures of the sibling relationship can give valuable information, such as ratings of the positivity (warmth/closeness) and negativity (conflict, rivalry, and relative status/power) of the relationship; however, the sibling relationship also includes when and how siblings interact with each other (Furman & Buhrmester, 1985; Allison & Campbell, 2015). Research on sibling relationships specifically involving DS would benefit from inclusion of reliable measures of sibling interactions that can

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provide valid and more objective data about the quality of the sibling relationship. The literature does present guides to reliably measure the sibling relationship by observing and assessing characteristics of sibling interactions such as the duration of a reciprocal interaction, the number of initiations and responses, the valence of each communicative event, and whether the communicative event is prosocial or agonistic (Abramovitch, Corter, & Lando, 1979; Abramovich, Stanhope, Pepler, and Corter, 1987; Knott, Lewis, and Williams, 1995; Lobato et al. 1987; Odom, Hoyson, Jamieson, and Strain, 1985; Kamps et al., 2002, Kryzak, Cengher, & Fienup, 2015). Observation can be less vulnerable to response bias and provides real-time demonstration of the sibling relationship, rather than reflective accounts gathered by self-report measures.

Summary

In summary, the sibling relationship is often one of the most influential relationships in a person's life. Although limited, the research presented shows that when one sibling has DS and the other is TD, the sibling relationship is affected by the social and communication skills of the sibling with DS and also the emotional coping/adjustment of the TD sibling. An effective way to address the behavioural and communication skills of the sibling with DS is through applied behavior analytic interventions. An effective way to address the emotional coping/adjustment of the TD sibling is through support group interventions. Although no such studies exist in the DS literature, research from the ASD literature suggests that combining both of these interventions into an integrated program can lead to improved quality of the sibling relationship. Finally, the sibling relationship may best be evaluated through observable measures of sibling interactions in addition to self-report measures.

The Current Study

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The current study sought to add to the current literature in several novel ways: 1) it looked at the effects of a tailored and integrated social skill support group on the sibling relationship between children with DS and their TD siblings; 3) it included observable measures of the sibling relationship in addition to self-report measures; and 4) it recorded the observable measures in both the group and home setting. The main research question was: how does a social skills support program integrating interventions for both the child with DS and their TD sibling affect the sibling relationship? If the communication/social skills of the child with DS improve and if the TD siblings gain emotional coping/adjustment skills, it was hypothesized that the sibling relationship would improve.

Method

Participants

This research was reviewed and approved by the institutional review board at Western University; a copy of the ethics approval form is found in Appendix A. Inclusion criteria required that participants were sibling dyads where one child is TD and one child has a diagnosis of DS, as determined by parent report. Both siblings were required to be between 5 and 17 years of age, as this age range represents the upper and lower limits of the study measures that were administered to participants. Participants were recruited from organizations in the London, Ontario region that provide services to families who have a child with DS, for example the London Down Syndrome Association. The principle investigator contacted these organizations (typically the program directors) via scripted email using email addresses posted on their public websites. A member of the organization (typically a secretary) distributed our study recruitment flyer on our behalf, usually by e-mail and/or by posting on their website. Interested families

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contacted the researchers and received a letter of information and a phone call to review details about participating in the study.

Sample

A total of three dyads signed the consent forms. One dyad withdrew from the study after week one of the intervention due to scheduling conflicts. Data from the remaining two sibling dyads that completed the study are reported here. The first dyad consisted of two sisters, Katie and Emma. Emma is the youth with DS and she was 14 years old at the time of the study. Katie is the TD sibling and she was 16 years of age at the time of the study. The second dyad consisted of two brothers, Connor and Greg. Greg is the child with DS and he was 6 years old at the time of the study. Connor is the TD sibling and he was 11 years of age.

Overall Settings

The social skills support group took place at Merrymount Children's Centre, a London, Ontario organization that provides various programming for children and their families. Merrymount is affiliated with the University of Western Ontario via the Mary J. Wright Centre. More detailed descriptions of the setting for the social skills support group is found in the Independent Variable section. Filling out of pre- and post- questionnaires took place in each family's home, in a quiet location deemed suitable by the family. Also in the home, the video recordings of siblings interacting took place in a quiet area where distractions could be minimized and there was room for the sibling pair to interact.

Dependent Variables: Assessments and Measures of Sibling Relationship

Self-Report Questionnaires. Two self-report measures were used to evaluate sibling relationship. The first self-report questionnaire used was The Sibling Inventory of Behaviour

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Revised (SIBR; Hetherington, Henderson, & Reiss, 1999), which has a version for Parents (SIBR-P) and for Siblings (SIBR-S). It was developed by Schaeffer and Edgerton (1981) and modified by Hetherington, Henderson, and Reiss (1999); it assesses behaviors of siblings toward each other and their relationship. The SIBR-P has two parts, with Part 1 assessing child A's behaviour towards child B and Part 2 assessing child B's behaviour towards child A. In our study, SIBR-P Part 1 assessed behaviors of the child with DS toward their TD sibling and SIBR-P Part 2 assessed behaviours of the TD sibling towards the child with DS. The SIBR-P (Part 1 and Part 2) and the SIBR-S each contain 32 items including: a 5-item empathy/concern scale, a 6-item companionship/involvement scale, a 6-item rivalry scale, a 5-item conflict/aggression scale, a 5-item avoidance scale, and a 4-item teaching/directiveness scale. Each item is answered on a 5-point Likert scale: 1 (never), 2 (seldom), 3 (sometimes), 4 (often), and 5 (always). A factor analysis indicated that the scales formed two larger factors, positivity (sum of teaching/directiveness, companionship, and empathy) and negativity (sum of aggression, avoidance, and rivalry) (Schaeffer & Edgerton, 1981). Psychometric properties of the SIBR are good. The reliability is robust with respect to Cronbach's alpha estimates and construct validity is also strong, as indicated by correlation with other measures of sibling relationship and also with comparison to observed sibling interactions (Volling, Brenda & Bandon, Alysia, 2005). A copy of the SIBR-P and SIBR-S can be found in Appendix B and C, respectively.

The second self-report questionnaire used was the Sibling Relationship Questionnaire Revised (SRQR: Furman & Buhrmester, 1985), which also has a version for Parents (SRQR-P) and for Siblings (SRQR-S). It was developed by Buhrmester and Furman (1985) to assess parent and sibling perceptions of the sibling relationship. It contains 42 questions which make up three main subscales evaluating the following dimensions of the sibling relationship:

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warmth/closeness, conflict, and relative power/status. The dimension subscale of warmth/closeness consists of seven underlying qualities: intimacy, prosocial behavior, companionship, affection, similarity, admiration of the sibling, and admiration by the sibling (Furman & Buhrmester, 1985). The dimension subscale of conflict can be divided into three underlying qualities: quarreling, antagonism, and competition (Furman & Buhrmester, 1985). The dimension subscale of relative power/status can be divided into two underlying qualities: nurturance and dominance. Each item on the SRQR is answered on a 5-point Likert scale: 1 (hardly at all), 2 (not too much), 3 (somewhat), 4 (very much), and 5 (extremely much). The construct validity of the instrument, as shown by correlation with observed sibling behaviours, and internal consistency, as measured by Cronbach's alpha, for these dimensions and the underlying qualities is strong (Derkman et al., 2010). A copy of the SRQR-P and SRQR-S can be found in Appendix D and E, respectively.

Direct Observation of Interactions. Each sibling dyad was video recorded while engaging together in three different types of activities for 5 minutes each: building blocks, board games, and crafts/colouring. This resulted in 15 minutes of recorded interactions. Three different activities/games were used to account for varying interests of the siblings and to increase ability to generalize any relevant findings. Building blocks engaged the siblings in semi-structured activity ideally requiring cooperation, board games require the siblings to interact in a turn-based manner of communication, and crafts/coloring offer the siblings a chance to be creative and more free-form in their interactions. The protocol for obtaining these video recordings is detailed later in the procedure section.

There are several studies that have validated coding guides of sibling interactions for the measurement of relationship quality (Abramovich, Stanhope, Pepler, & Corter, 1987; Kamps et

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al., 2002; Knott, Lewis, & Williams, 1995; Kryzak et al., 2015; Lobato et al. 1987; Odom, Hoyson, Jamieson, & Strain, 1985). The current study combined these offerings to come up with a coding guide to apply to observed interactions between the sibling participants, which can be found in Appendix F. First, the researchers coded the type and frequency of social–communicative behaviors emitted by either the child with DS or the sibling. A social–communicative behavior broadly refers to behavior emitted by either child directed to the other child, including vocalizations and use of gestures. Secondly, the researchers coded whether the social-communicative behaviour was an initiation or a response. An initiation refers to any social-communicative behavior not preceded within 3 s by a social-communicative behavior from the sibling. Responses are any social-communicative behavior that occurs specific to and directed towards the sibling within 3 s of a preceding behavior from the other sibling. Third, the total duration for which the siblings are engaging in reciprocal interaction with each other was calculated. A reciprocal interaction was defined as an initiation and all responses that followed, where each response occurred within 3 s or less of the previous response. Lastly, the researchers coded whether the social-communicative behavior was prosocial or agonistic. An example of a prosocial social-communicative behaviour would be verbal statements of approval or admiration of the sibling or his/her behaviour. An example of an agonistic social-communicative event would be assertive physical contact and teasing, name calling, or unfavorable judgements. Overall, the study will report the following summative outcomes for each time point: 1) the total number of initiations and responses for each individual sibling and each sibling pair; 2) the total duration of reciprocal interaction for each sibling pair; and 3) the number of prosocial versus agonistic communication events for each individual sibling and each sibling pair.

Independent Variable: Social Skills Support Group Intervention

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General Itinerary. The social skills support group is a two-hour program, taking place over 10 weeks. For the first hour of each session, individualised skills intervention was provided for the children with DS and a concurrent support group was provided for the TD siblings. During individualized skills intervention, children with DS received applied behavioral analytic (ABA) instruction around social, communication, and play skills that are important for interacting with their siblings (e.g. turn taking, reciprocal commenting, and sitting appropriately). During the TD sibling support group, siblings were provided lessons that covered a specific topic each week. For the second hour of each session, all children attended recreation time together. During recreation time, children completed relay races, sibling interaction activities, and whole group activities.

Setting. The individualized skills instruction for the children with DS took place in a large room with a multitude of areas and materials appropriate for behavioural interventions, including couches, tables and chairs, books, play kitchen and workbench, board games, mats, a sink area, etc. The support group for TD siblings took place in an adjacent room equipped with tables and chairs and a sink area. The recreation hour took place in the same room as the individualized skills instruction.

Interventionists. The principal investigator is a doctoral level Board-Certified Behavior Analyst (BCBA-D) and was responsible for approving the programming and delivery of the support group for TD siblings and the individualized skills instruction for the siblings with DS, as described below. Other interventionists involved in the delivery of the social skills support group were all undergraduate or masters level students of Western University and were involved with the study in a volunteer, work-study, or research assistantship capacity. All individuals were trained in basic ABA techniques by the principal investigator.

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TD Sibling Support Group. The curriculum for the support group for TD siblings was based on the established SibShops program, developed by Meyer and Vadasy (1994). The first two weeks were focused on the participants getting to know each other. Then the group moved into topics such as sharing and talking about feelings, developmental disability/DS education, coping strategies, meeting and talking with an adult who has a sibling with DS, positive self-esteem, and why you are important to your sibling. The last week was focused on reflection/conclusion. Materials for the sibling support group included personalized workbooks with weekly activities, board games, playing cards, art supplies, a ball, candy, certificates (e.g. good listening), books about DS, a shoe box, and DS trivia questions. The support group was run by a master's level counselling psychology student, with other interventionists available to help as needed.

Individualized Skill Instruction for Siblings with DS. During the first week of the program, interventionists collected baseline data about the skills of the child with DS related to social skills important in interacting with their siblings. For younger children with DS, skills included taking their turn during a game, allowing someone else to take a turn, responding to their name being called, making reciprocal statements (e.g. volunteer says, "My name is --," child responds, "My name is --"), initiating comments (e.g. "I have this game at home"), requesting, and use of eye contact. For older children with DS, skills included taking turns, emotional regulation, requesting, and staying on task. Baseline data were used to develop individualized intervention plans targeting two to three skills for each child with DS. Intervention was embedded in game play or other activities, such as drawing pictures. Sometimes children worked one-on-one with an interventionist and other times they played games with peers with the interventionist's support. Intervention involved setting up a context,

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delivering an instruction, prompting if necessary, reinforcing behavior, and repeating this structure for 5–10 opportunities. Prompts were individualized for each child and the target response and faded from most to least. Physical and gestural prompts were used for turn taking, while visual (textual or pictorial) prompts were used for expressive communication and eye contact. Prompt fading occurred when children performed at 80% or higher in a session of 5–10 opportunities. Throughout the 10-week program, the principal investigator provided weekly feedback for interventionists, including instructions, modeling, practicing, and feedback on implementation of intervention. The principal investigator also examined treatment data each week and changed programs (i.e., targets and prompt levels) depending upon the child's performance. The materials for the skills intervention included datasheets, timers, writing tools, index cards/wipe boards for visual prompts, art supplies (e.g. markers and construction paper), board games (e.g. Candyland™), and edibles. The individualized skills instruction was run by a master's level counselling psychology student and the principal investigator, with other interventionists available to help as needed.

Combined Recreation Hour. During recreation time, activities were intended to mimic “field days” and physical education classes at schools, including stretching, relay races, cooperative games between siblings. Examples include both siblings in a hula hoop trying to walk through an obstacle course, catching a ball, or bean bag toss, freeze dance, Simon says, and red rover. Games were those that would likely be played in other settings by peers and are appropriate for children of varied ages and abilities. Recreation time materials included timers, music player, art supplies, cones, and a variety of other play materials. The recreation hour was run by a master's level counselling psychology student, with the principal investigator and other interventionists available to help as needed.

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Research Design

A pre-post design was used to measure the sibling relationship through self-report questionnaires filled out by the parents and the TD siblings. A time-series AB design was used to measure the sibling relationship via direct observations of social–communicative interactions. Results are presented graphically and discussed as descriptive case series.

Procedure

Assessment Schedule. Table 1 outlines the general assessment timeline followed and described here. Following expressed interest, all families received packets containing a letter of information, consent/assent forms, and intake forms designed to describe the general demographics of the participants. A research assistant contacted the family by phone to go through these materials. If the parents gave consent and the child gave assent, the researchers scheduled a week 0 pre-baseline assessment in the participant's home setting. During the week 0 pre-baseline assessment, the consent/assent forms were checked for completeness and collected while the parents and the TD siblings completed the self-report questionnaires. During the week 0 pre-baseline assessment, researchers also video recorded each sibling dyad playing the three different types of games for the observations of sibling interactions. Week 1 baseline assessment occurred in the group setting on day 1 of the intervention; sibling dyads were pulled into a private room and video recorded playing the three different types of games during recreation hour of the social skills support group program. Recreation time was held before the interventions during week 1 (so that this measurement could be used as pre-intervention baseline) and after the interventions for each subsequent meeting. During week 4 and week 8 of the social skills support group intervention, researchers completed intervention assessments in the home setting to video record each sibling dyad playing the three different types of games for

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observation of sibling interactions. Week 10 post-intervention assessment was held in the group setting, where again sibling dyads were also pulled into a private room and video recorded playing the three different types of games during recreation hour. At week 10, parents and TD siblings were given the self-report questionnaires to fill out again that night. The week 14 follow-up assessment was completed 4 weeks after the intervention ended and included video recording each sibling dyad playing the three different types of games and collection of the post-intervention self-report questionnaires filled out at week 10.

Video Recording Protocol and Evaluation. As discussed above, there were three main categories of games/activities (i.e. building blocks, board games, and crafts/colouring) that the sibling dyads were recorded playing. Each category had at least three different options for the siblings to choose from. For example, building blocks options included LEGO, wooden blocks, or Silly Star Connectors™. Each recording session, the sibling pair was offered a choice of which category and option of game within that category they wanted to play first, second, and third. Researchers used scripted instructions to ready the siblings for the recording session. The siblings told the researcher which category and game they wanted to play first, and the researcher then put that game in front of the siblings. The 5-min timer and the coding of behaviors started when either one of the siblings first touched the game materials. If the siblings were not playing together, the researcher gave a prompt every minute of, “[sibling name], would you like to play with your brother/sister?”, alternating which sibling name was said. Researchers tried to provide minimal assistance and interference during game play. For example, if a child could not open a box, the researcher would provide brief assistance and step away. If the children did not independently engage in the activity, the researchers provided direct assistance in the form of modeling or physical prompting. After 5 minutes with one game as indicated by the timer, the

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researcher announced that it was time to clean up the current game and play a new game. The camera was not stopped, but when one of the siblings engaged with the new game materials, the timer and coding of behaviors began again.

The video recorded sessions of the siblings playing games were scored by the primary researcher by recording on data sheets. See Appendix F for a copy of the recording sheets used. The following was scored: 1) the total number of initiations and responses for each individual sibling and each sibling pair; 2) the total duration of reciprocal interaction for each sibling pair; and 4) the number of prosocial versus agonistic communication events for each individual sibling and each sibling pair. A research assistant/volunteer independently scored a randomly selected sample of 30% of the sessions and their findings were compared with those of the primary researcher for each of the reported measures. From this, interobserver agreement (IOA) was calculated for initiations, responses, prosocial communication events, and total reciprocal interaction time by dividing the smaller count by the larger count and multiplying by 100 (Cooper et al., 2007). IOA for initiations averaged 83% (range, 30-100%) and for responses averaged 80% (range, 50-100%). IOA for agonistic interactions averaged 96% (range, 82-100%). IOA for total reciprocal interaction time averaged 80% (range 50-95%).

Results

Katie (TD sibling) and Emma (sibling with DS)

Self-Report Questionnaires.

Sibling Inventory of Behaviour Revised (SIBR). Figure 1 shows the results of the SIBR-P Part 1, SIBR-P Part 2, and SIBR-S for Katie and Emma. For the SIBR-P Part 1, which assessed the parent's report of how Emma behaves towards Katie, the negativity factor (sum of the

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aggression, avoidance, and rivalry subscales) decreased as did the positivity factor (sum of teaching/directiveness, companionship, and empathy subscales). Similarly, for the SIBR-P Part 2, which assessed the parent's report of how Katie behaves towards Emma, the negativity factor decreased, as did the positivity factor. For the SIBR-S, which assessed Katie's report of how she behaves towards Emma, the negativity factor decreased, while the positivity factor remained the same.

Sibling Relationship Questionnaire Revised (SRQR). Figure 2 shows the results of the SRQR-P and SRQR-S for Katie and Emma. The SRQR-P, which assessed the parent's report of the sibling relationship between Emma and Katie, showed an increase in warmth/closeness and a decrease in relative power/status and conflict. The SRQR-S, which assessed Katie's report of the sibling relationship between her and Emma, showed a decrease in relative power/status and an increase in warmth/closeness and conflict.

Direct Observation of Interactions.

Unfortunately, there were technical difficulties with the recording equipment and, during week 4, only 30 seconds of sibling interactions were recorded for each game. Thus week 4 is not included in the results for Katie and Emma. All three activities (building blocks, board games, and crafts/labelling) showed similar trends with no interactions apparent. Additionally, both Emma and Katie showed consistent trends on all reported outcomes. Consequently, the results were combined and totalled for the sibling pair over the whole 15 minutes of interaction.

Figure 3 shows the total frequency of initiations and responses, total percentage of prosocial interactions, and total reciprocal interaction time for Katie and Emma. When comparing pre-intervention to post-intervention, there was a decreasing trend for both initiations

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and responses (the smallest difference was a decrease of 3 between pre and post frequency and the largest difference was a decrease of 41 between pre and post frequency). Prosocial interactions remained relatively stable, although there was a slight increasing trend, especially in the group setting. The amount of reciprocal interaction time decreased, which aligns with the decreasing trend also seen in initiations and responses.

Connor (TD sibling) and Greg (sibling with DS)

Self-Report Questionnaires.

Sibling Inventory of Behaviour Revised (SIBR).

Figure 4 shows the results of the SIBR-P Part 1, SIBR-P Part 2, and SIBR-S for Connor and Greg. For the SIBR-P Part 1, which assessed the parent's report of how Greg behaves towards Connor, the negativity factor (sum of the aggression, avoidance, and rivalry subscales) decreased as did the positivity factor (sum of teaching/directiveness, companionship, and empathy subscales). Similarly, for the SIBR-P Part 2, which assessed the parent's report of how Connor behaves towards Greg, the negativity factor decreased, as did the positivity factor. For the SIBR-S, which assessed Connor's report of how he behaves towards Greg, the negativity factor decreased, as did the positivity factor.

Sibling Relationship Questionnaire Revised (SRQR).

Figure 5 shows the results of the SRQR-P and the SRQR-S for Connor and Greg. The SRQR-P, which assessed the parent's report of the sibling relationship between Connor and Greg, showed an increase in conflict and a decrease in relative power/status and warmth/closeness. The SRQR-S (assessing Connor's report of the sibling relationship between

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him and Greg) showed no change in warmth/closeness, a decrease in relative status/power, and an increase in conflict.

Direct Observation of Interactions.

As in the other dyad, all three activities (building blocks, board games, and crafts/colouring) showed similar trends with no interactions apparent. Connor and Greg both also showed consistent trends on all reported outcomes. Thus, the results were again combined and totalled for the sibling pair over the whole 15 minutes of interaction.

Figure 6 shows the total frequency of initiations and responses, total percentage of prosocial interactions, and the total reciprocal interaction time for Connor and Greg over the course of the study. When comparing pre-intervention to post-intervention, there was a distinct increasing trend for both initiations and responses (the smallest difference was an increase of 9 between pre and post frequency and the largest difference was an increase of 70 between pre and post frequency). Prosocial interactions increased, which was especially striking in the group setting. Reciprocal interaction time also increased, especially in the group setting, which aligns with the increase seen in initiations and responses.

Discussion

The current study is pilot research investigating how a social skills support program integrating interventions for both the child with DS and their TD sibling affects the sibling relationship. One of the only other studies to look at a similar question is Kryzak et al. (2015), who examined the effects of such a social skills support program on interactions between children with ASD and their TD siblings. The social skills support group in the current study was held for 2 hours every week, for a total of 10 weeks. For the first hour of each session,

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instruction was provided for the children with DS using ABA-based interventions designed to improve social, communication, and play skills important in reciprocal relationships (Bauer, Jones, & Feeley, 2014; Feeley, Jones, Blackburn, & Bauer, 2011). Concurrently, a support group was provided for the TD siblings based on curriculum proven to improve social and emotional coping/adjustment (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005; Roberts et al., 2015; Roberts, Ejova, Giallo, Strohm, & Lillie, 2016). For the second hour of each session, all children attended recreation time together where they could interact and practice the skills learned. The dependant variables used to measure sibling relationship included two questionnaires, the SIBR and SRQR, and also direct observations of sibling interactions.

The current study builds on previous research (Kryzak et al., 2015) by using the SIBR-R and the SRQR, which are validated measures of sibling relationship, to help evaluate the success of the intervention (Derkman et al., 2010; Volling, Brenda & Blandon, Alysia, 2005). There was a decrease in both the negativity and positivity factors when looking at the SIBR-P (Part 1 and Part 2) and the SIBR-S for Emma and Katie and for Connor and Greg. The social skills support program's curriculum focused mostly on coping with negative emotions and this could be reflected in these questionnaire results. For example, one of the main elements of the social skills program curriculum specifically for Emma was emotional recognition, emotional regulation, and, specifically, how to handle negative emotions without avoidance or conflict. The results of the SIBR-P Part 1 suggest that the intervention may have helped Emma with attenuation of negative behaviors towards Katie. Unrelated to the intervention, it could be that both positivity and negativity factors decreased because of regression to the mean or because the parent was more aware of and honest about behaviours in responding to the post-intervention questionnaire.

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The SRQR-P for Katie and Emma revealed that after the intervention, warmth/closeness of the relationship was higher, conflict was less, and relative status/power was less (meaning that after the intervention, no one sibling was treated better or had more influence in the relationship). These results are encouraging as to the intervention having a positive effect on the sibling relationship, as reported by Emma and Katie's parent. Katie's results from the SRQR-S are also encouraging, as she too reported that the warmth/closeness in the relationship increased and the relative status/power decreased. However, Katie reported that conflict increased slightly after the intervention. For Connor and Greg, the SRQR-P and SRQR-S also showed that conflict increased following the intervention. It is curious why conflict would be reported to increase in the SRQR, but not in the SIBR (conflict was a subscale of the larger factor of negativity). This could be due to operational definitions of conflict and the way in which the questions are asked. Especially because there is a discrepancy between the parent and sibling report of conflict for Emma and Katie, a slight increase in conflict could also be situational. That is, that there could have been an external event that increased the frequency of or even just perception of conflict in the post-intervention measurement unrelated to the intervention.

While the trends from pre-intervention to post-intervention were similar for both sibling dyads, it is important to note that the raw scores for Katie and Emma in positivity factors in both the SIBR and SRQR were consistently higher than for Connor and Greg. This speaks to the fact that Katie and Emma had a more positive relationship overall, regardless of the intervention. This is important in the interpretation of the direct observations of behaviours, which are discussed next.

Unlike the questionnaire results, which were quite similar between the sibling dyads, the results of the direct observation measures were noticeably different between the two sibling

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dyads. Kryzak et al. (2015) also reported that there were varied trends seen in the observable behavioural observations of their 11 sibling dyad study participants. All reported outcomes (initiations and responses, prosocial interactions, and reciprocal interaction time) increased for Connor and Greg in both the home and group settings. These results are encouraging as to the intervention having a positive effect on the outward manifestation of the sibling relationship between Connor and Greg. For Katie and Emma, all reported outcomes decreased or remained consistent in both the home and group setting. Although it is a possible explanation, Katie and Emma's results do not inherently speak to a failure of the intervention to improve the sibling relationship. The researchers noted that Emma and Katie had tended to choose the same games in each category across the recording sessions, whereas Connor and Greg tended to choose different games in each category across the recording sessions. It is plausible that Emma and Katie became familiar with the activities as they played it each week and so the lowered amount of interaction was not because the intervention hurt the sibling relationship, but rather because Emma and Katie became used to the games and had to communicate less to play them.

Most likely, however, as discussed in the previous section, a main reason for the discrepancy in observable results between the sibling dyads could be that Katie and Emma had a more positive relationship to begin with. This suggests that the intervention is best designed for siblings starting with a more negative or less interactive sibling relationship. Future studies may be informed to employ more directed purposive sampling for sibling dyads with a less strong sibling relationship.

The current study is not without limitations, many of them stemming from the fact that it was a small pilot study. Moving forward, however, the limitations of the current study can be used to direct future research. One limitation was the overall research design, which was not able

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to include a comparison group or employ randomization. This means that any changes in the results of the questionnaires and direct observations cannot be concretely attributed to the social skills support group intervention. Another large limitation was the small sample size, which further confines the detection of significant changes. Reasons for small sample size relate to the already small and targeted population of children with DS with TD siblings. While the two sibling dyads that were recruited provided interesting results, without a larger sample size we cannot make clear conclusions or examine fully other things that may affect results, such as demographic factors like age, gender, and sibling order. Future studies would do well to try and improve recruitment. Ideas to achieve this include wider dispersal of recruitment materials, broader inclusion criteria (for example, including children with other developmental disabilities in addition to DS), and alteration to the time/travel commitment of the program (as evidenced by one dyad withdrawing from the study, some families may find it hard to commit to two hours a week for 10 weeks).

There may have been some limitations with both dependant variables used, the questionnaires and the direct observation of interactions. While the SIBR and the SRQR both have strong reliability and validity (Derkman et al., 2010; Volling, Brenda & Bandon, Alysia, 2005), it is not well defined whether they are suited for inferences about the success of a treatment or if they are simply meant to assess a population. Additionally, as discussed in interpreting the decrease of both the positivity and negativity scales, it could be that the factors assessed in the questionnaire measures were not best aligned to measure the success of the curriculum of the program in improving the sibling relationship. Finally, for any self-report measures, especially those done only pre- and post-intervention in a small number of

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participants, results are situational and changes in the results may be due to other uncontrolled variables.

Although important to include, results from direct observation of interactions, especially those which include affective responses, must be approached with caution for several reasons. First, the reliability for these measures is less as demonstrated by the lower ranges of IOA found in this and other studies (Abramovich, Stanhope, Pepler, & Corter, 1987; Kamps et al., 2002; Knott, Lewis, & Williams, 1995; Kryzak et al., 2015; Odom, Hoyson, Jamieson, & Strain, 1985). This could be a result of practical issues such as camera angle in combination with the subjectivity of judging small movements that may count as initiations or responses and facial expressions that may indicate prosocial or agonistic intent. Additionally, the research assistant coder was not blind to the purpose of the study and would have been able to tell whether the videos were pre or post intervention. As well, the degree of control needed in the research protocol (type of games, presence of the researcher, etc.) leads to forced and artificial interactions. As an example of this, especially for Greg and Connor, many comments were directed at the researcher, and thus not coded as interaction between the sibling. Natural interactions by the siblings may better reflect any influence of the social skills support group. It was also clear that the observed interactions were vulnerable to external events and influences having nothing to do with the intervention. For example, week 8 recordings from Emma and Katie show a dip in reciprocal interaction time. The researcher learned that the TD sibling had gotten back very late from a trip; her tiredness was clear in the videos and appeared to impact the measure outside of any influence of the intervention. Future studies may benefit from multiple camera angles, recording subjects from behind two-way glass, and use of blind coders.

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There may have also been limitations in the independent variable of the social skills support program, specifically with the fidelity of program. Although the curriculum for the ABA intervention skills instruction for the children with DS, the TD sibling support group, and the combined recreation hour was based on previous studies, the extent to which the curriculum was consistently followed was not directly measured in this pilot study. Fidelity measures may be important in future research.

Summary

There were no highly stable trends across the two participating sibling dyads that suggested the social skills support group may have wholly improved the sibling relationship. However, there were some results suggesting that the intervention may have helped improve small aspects of the sibling's relationship in each sibling dyad. Overall, this pilot study shows some preliminary evidence that a social skills support group could help to improve the sibling relationship and suggests the need for larger, randomized control trials to further demonstrate the most beneficial programming to improve and foster the sibling relationship between siblings where one has a diagnosis of DS. Improving the sibling relationship is important because a strong sibling relationship nurtures individuals' social, cognitive, and psychosocial development and bolsters the functioning of the whole family (Floyd et al., 2009; Noller, 2005; Milevsky & Heerwagen, 2013; Minuchin, 1974; Seltzer et al., 1991). Fostering a strong sibling relationship may also be especially relevant as individuals with DS live longer and rely more on their TD sibling(s) for care later in life (Dew et al., 2004; Orsmond & Seltzer, 2007).

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SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

Table 1

Study Procedure Overview

PRE-INTERVENTION		INTERVENTION		POST-INTERVENTION	
Week 0	Week 1	Week 4	Week 8	Week 10	Week 14
<i>Parent/Caregiver</i> Consent Intake Form SIBR-P SRQ-P	<i>TD Sibling</i> Video Recording	<i>TD Sibling</i> Video Recording	<i>TD Sibling</i> Video Recording	<i>Parent/Caregiver</i> SIBR-P SRQ-P	<i>TD Sibling</i> Video Recording
<i>TD Sibling</i> Assent SIBR-S SRQ-S Video Recording	<i>Sibling with DS</i> Video Recording	<i>Sibling with DS</i> Video Recording	<i>Sibling with DS</i> Video Recording	<i>TD Sibling</i> SIBR-S SRQ-S Video Recording	<i>Sibling with DS</i> Video Recording
<i>Sibling with DS</i> Assent Video Recording				<i>Sibling with DS</i> Video Recording	

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

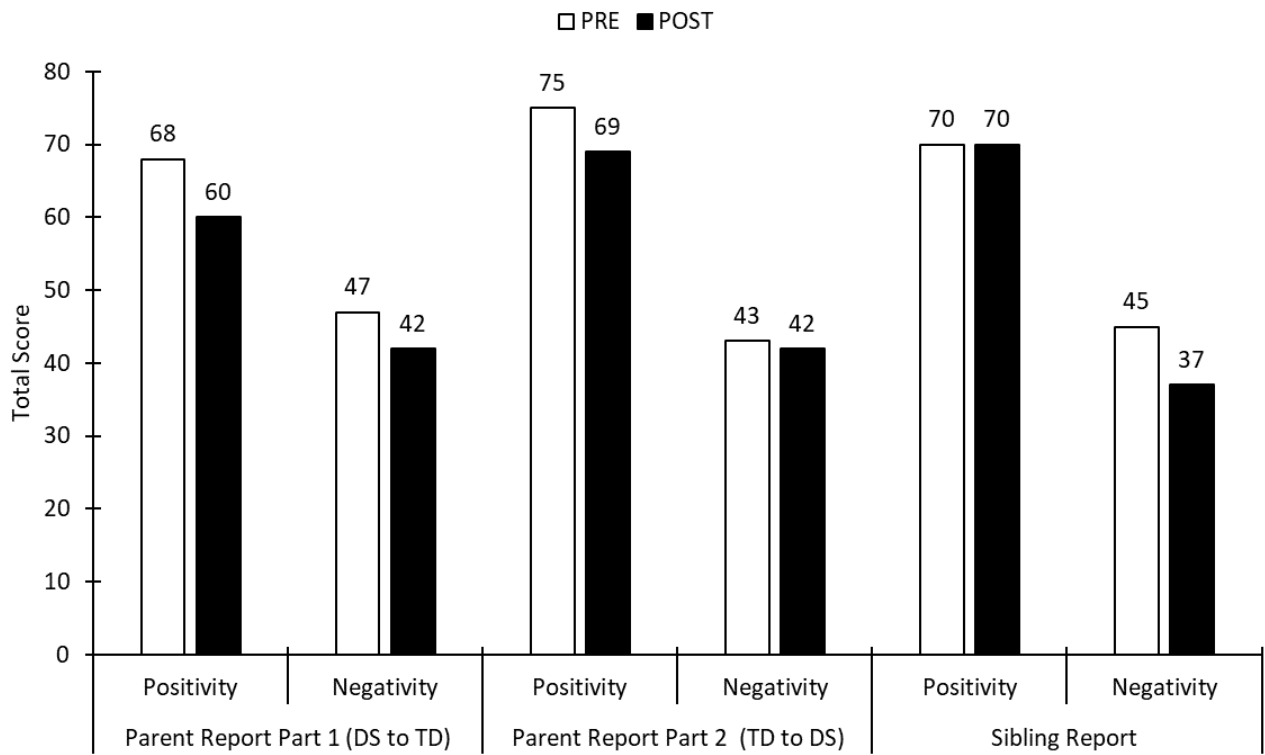


Figure 1. Katie and Emma: Total scores on Sibling Inventory of Behaviour Revised (SIBR) factors.

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

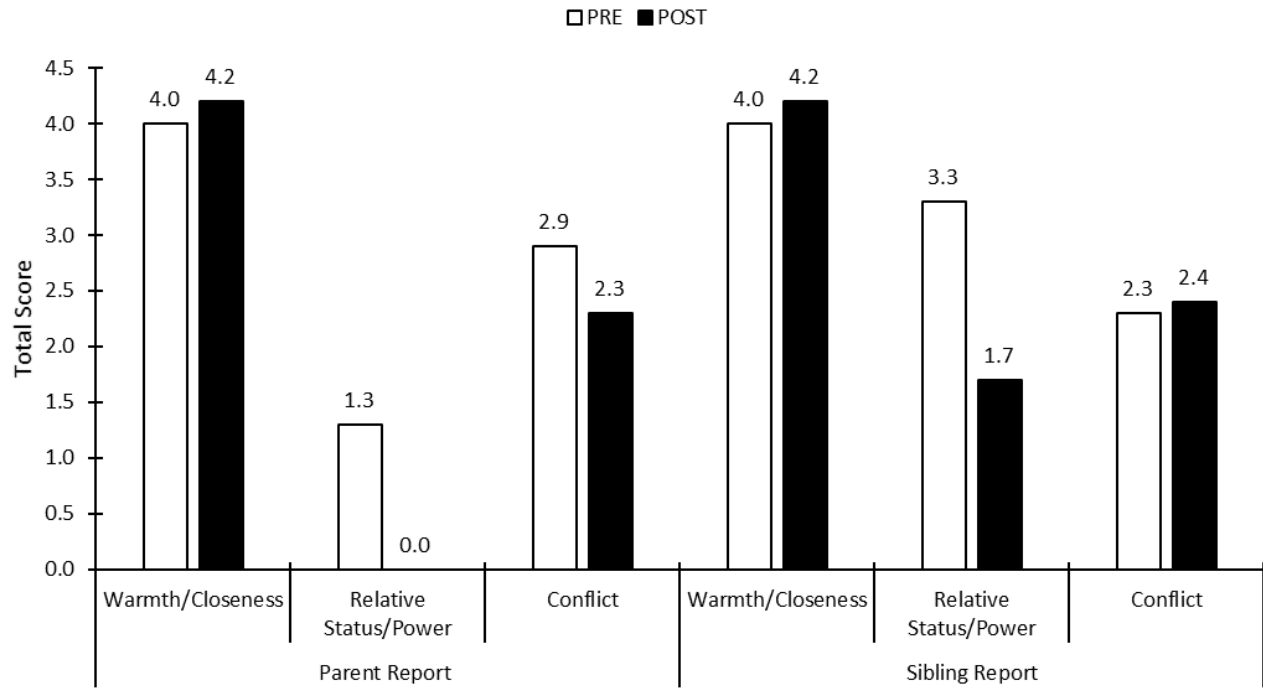


Figure 2. Katie and Emma: Total scores on Sibling Relationship Questionnaire Revised (SRQR) subscales.

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

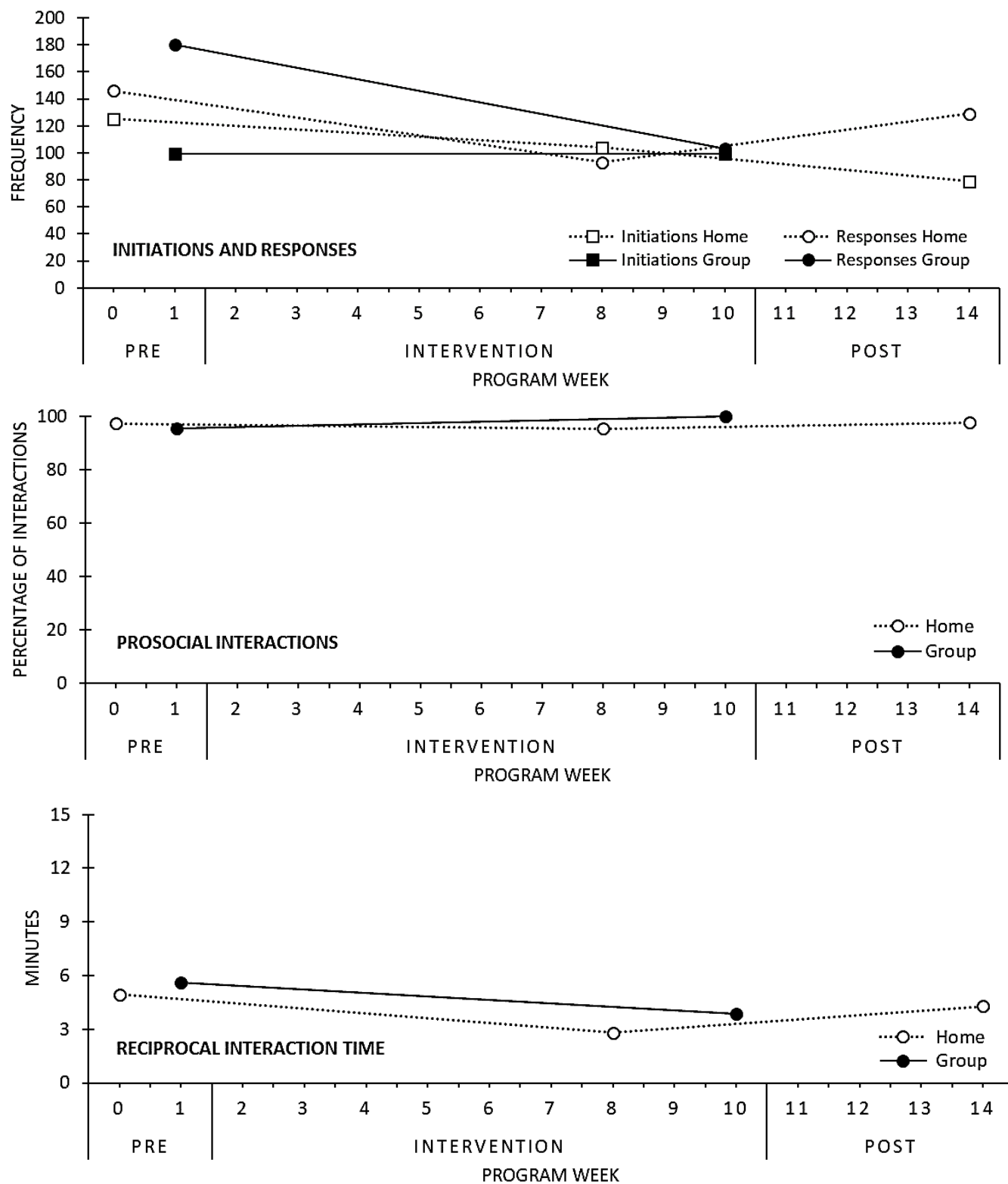


Figure 3. Katie and Emma: Frequency of initiations and responses, percentage of prosocial interactions, and reciprocal interaction time.

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

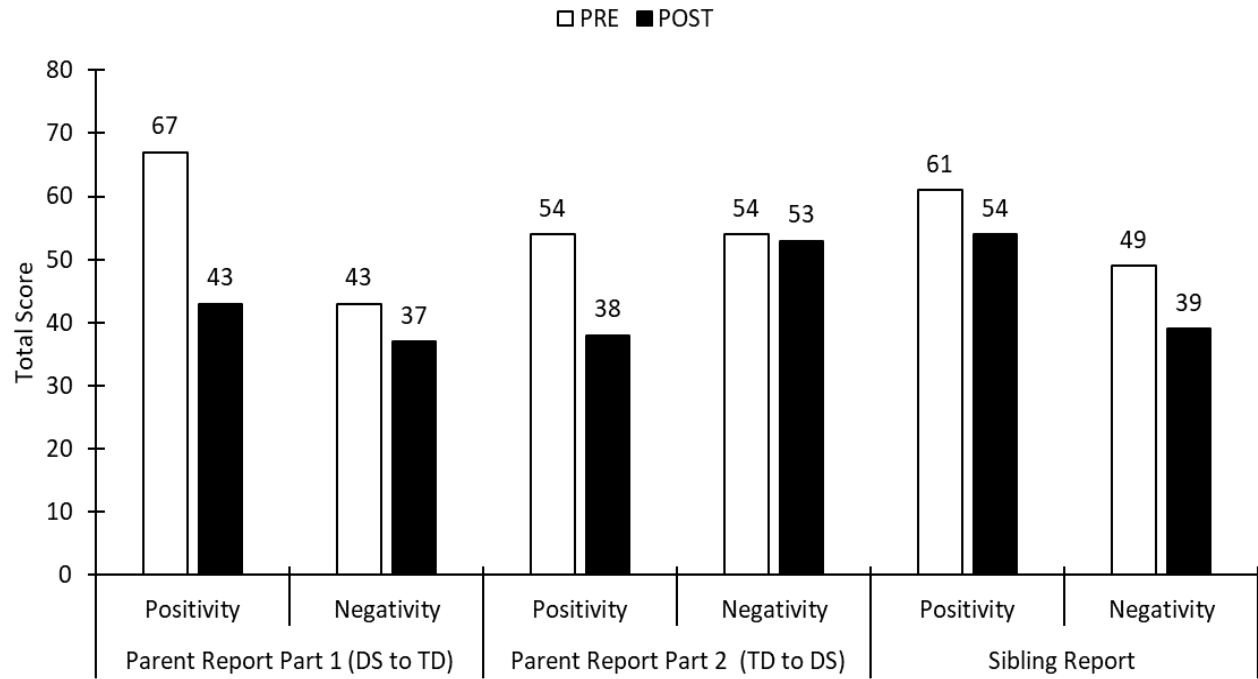


Figure 4. Connor and Greg: Total scores on Sibling Inventory of Behaviour Revised (SIBR) factors.

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

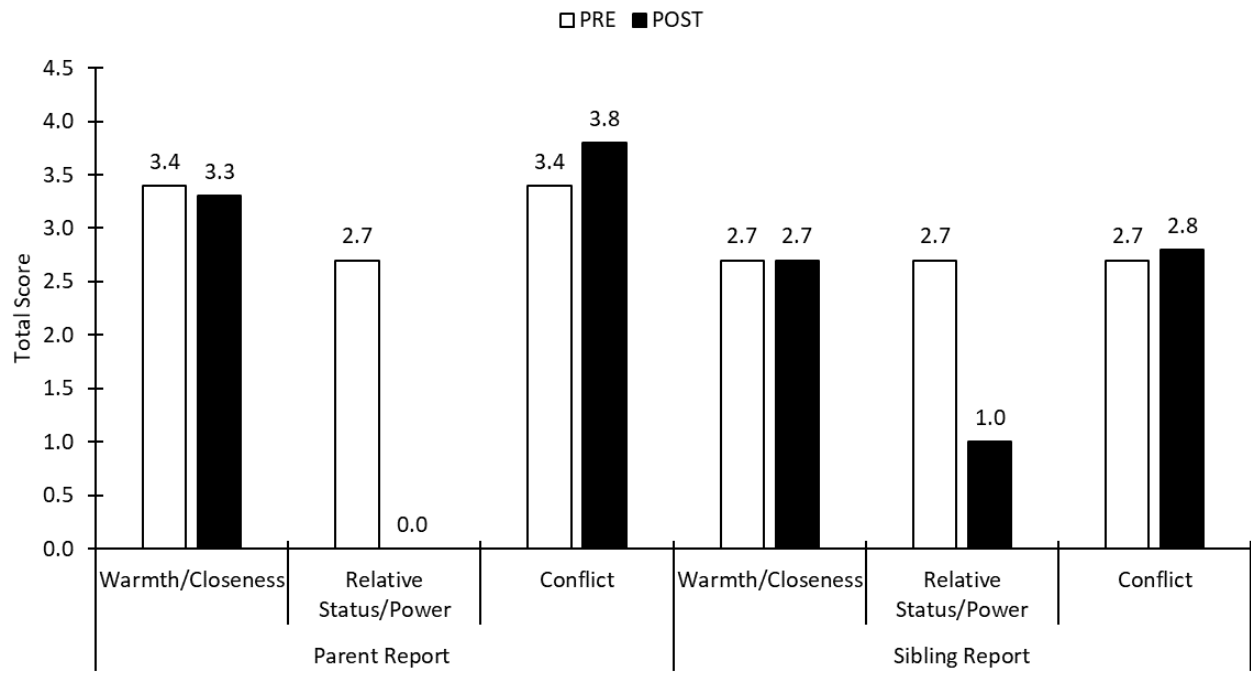


Figure 5. Connor and Greg: Total scores on Sibling Relationship Questionnaire Revised (SRQR) subscales.

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

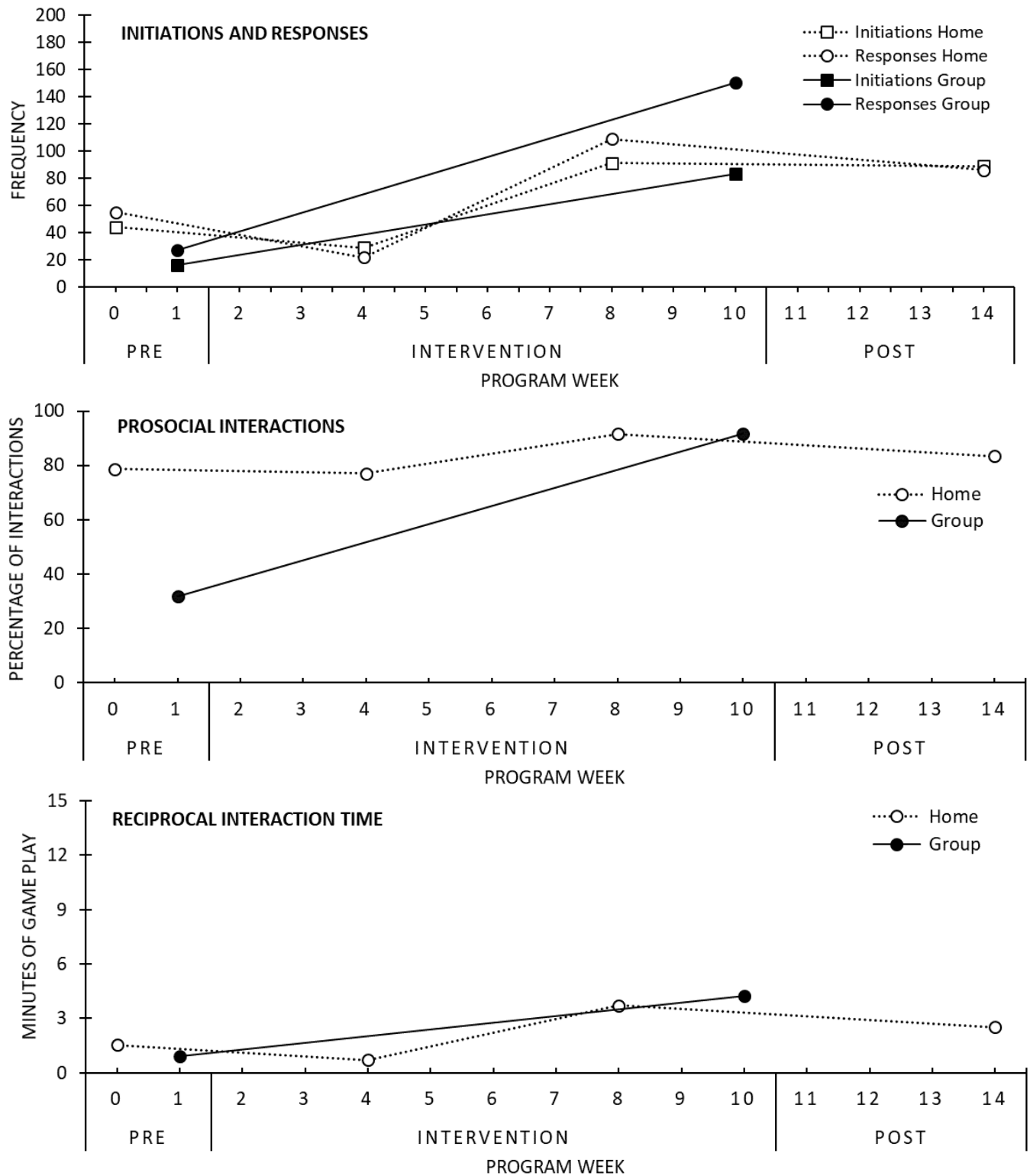


Figure 6. Connor and Greg: Total frequency of initiations and responses, total percentage of prosocial interactions, and total reciprocal interaction time.

Appendix A



Date: 11 February 2019

To: Dr. Nicole Neil

Project ID: 108609

Study Title: Evaluation of a Social Skills Program for Children with Developmental Disabilities and their Siblings: Pilot and Randomized Controlled Trial

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: 01/Mar/2019

Date Approval Issued: 11/Feb/2019

REB Approval Expiry Date: 14/Feb/2020

Dear Dr. Nicole Neil,

The Western University Non-Medical Research Ethics Board has reviewed this application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyzynski, Research Ethics Coordinator, on behalf of Prof. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B

Sibling Inventory of Behavior Revised - Parent**Part 1**

For each item, circle the number that shows how often your child with a developmental disability behaves in that way toward his/her sibling(s) without a developmental disability who is/are attending the Social Skills Program (and no other sibling(s)).

1	2	3	4	5
Never	Seldom	Sometimes	Always	Often

How often your child **with** a developmental disability.....

1. Is pleased by the progress your child without a developmental disability makes	1	2	3	4	5
2. Teases or annoys your child without a developmental disability	1	2	3	4	5
3. Gets angry with your child without a developmental disability	1	2	3	4	5
4. Accepts your child without a developmental disability as a playmate	1	2	3	4	5
5. Is embarrassed to be with your child without a developmental disability in public	1	2	3	4	5
6. Wants your child without a developmental disability to succeed.	1	2	3	4	5
7. Stays away from your child without a developmental disability if possible	1	2	3	4	5
8. Gets ideas for things they can do together	1	2	3	4	5
9. Fusses and argues with your child without a developmental disability	1	2	3	4	5
10 Has fun at home with your child without a developmental disability	1	2	3	4	5

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

11 Acts ashamed of your child without a developmental disability	1	2	3	4	5
12 Shows sympathy when things are hard for your child without a developmental disability	1	2	3	4	5
13 Frowns or pouts when your child without a developmental disability has be with him/her	1	2	3	4	5
14 Teaches your child without a developmental disability new skills	1	2	3	4	5
15 Helps your child without a developmental disability adjust to a new situation	1	2	3	4	5
16 Treats your child without a developmental disability as a good friend	1	2	3	4	5
17 Tries to avoid being seen with your child without a developmental disability	1	2	3	4	5
18 Is concerned for the welfare and happiness of your child without a developmental disability	1	2	3	4	5
19 Makes plans that include your child without a developmental disability	1	2	3	4	5
20 Hurts the feelings of your child without a developmental disability	1	2	3	4	5
21 Tries to comfort your child without a developmental disability when s/he is unhappy or upset	1	2	3	4	5
22 Shares secrets with your child without a developmental disability	1	2	3	4	5
23 Baby-sits and cares for your child without a developmental disability	1	2	3	4	5
24 Tattles on your child without a developmental disability	1	2	3	4	5
25 Is jealous of your child without a developmental disability	1	2	3	4	5
26 Has physical fights with your child without a developmental disability (not just for fun)	1	2	3	4	5
27 Is nosy and has to know everything about your child without a developmental disability	1	2	3	4	5
28 Tries to teach your child without a developmental disability how to behave	1	2	3	4	5

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

29 Takes advantage of your child without a developmental disability	1	2	3	4	5
30 Blames your child without a developmental disability when something goes wrong	1	2	3	4	5
31 Is very competitive against your child without a developmental disability	1	2	3	4	5
32 Resents your child without a developmental disability	1	2	3	4	5

Part 2

For each item, please think about how you child without a developmental disability, who is attending the Social Skills Program, acts toward his/her sibling with a developmental disability (and no other siblings).

1	2	3	4	5
Never	Seldom	Sometimes	Always	Often

How often your child without a disability.....

1. Is pleased by the progress your child with a developmental disability makes	1	2	3	4	5
2. Teases or annoys your child with a developmental disability	1	2	3	4	5
3. Gets angry with your child with a developmental disability	1	2	3	4	5
4. Accepts your child with a developmental disability as a playmate	1	2	3	4	5
5. Is embarrassed to be with your child with a developmental disability in public	1	2	3	4	5
6. Wants your child with a developmental disability to succeed.	1	2	3	4	5

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

7. Stays away from your child with a developmental disability if possible	1	2	3	4	5
8. Gets ideas for things they can do together	1	2	3	4	5
9. Fusses and argues with your child with a developmental disability	1	2	3	4	5
10 Has fun at home with your child with a developmental disability	1	2	3	4	5
11 Acts ashamed of your child with a developmental disability	1	2	3	4	5
12 Shows sympathy when things are hard for your child with a developmental disability	1	2	3	4	5
13 Frowns or pouts when your child with a developmental disability has be with him/her	1	2	3	4	5
14 Teaches your child with a developmental disability new skills	1	2	3	4	5
15 Helps your child with a developmental disability adjust to a new situation	1	2	3	4	5
16 Treats your child with a developmental disability as a good friend	1	2	3	4	5
17 Tries to avoid being seen with your child with a developmental disability	1	2	3	4	5
18 Is concerned for the welfare and happiness of your child with a developmental disability	1	2	3	4	5
19 Makes plans that include your child with a developmental disability	1	2	3	4	5
20 Hurts the feelings of your child with a developmental disability	1	2	3	4	5
21 Tries to comfort your child with a developmental disability when s/he is unhappy or upset	1	2	3	4	5
22 Shares secrets with your child with a developmental disability	1	2	3	4	5
23 Baby-sits and cares for your child with a developmental disability	1	2	3	4	5
24 Tattles on your child with a developmental disability	1	2	3	4	5
25 Is jealous of your child with a developmental disability	1	2	3	4	5

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

26	Has physical fights with your child with a developmental disability (not just for fun)	1	2	3	4	5
27	Is nosy and has to know everything about your child with a developmental disability	1	2	3	4	5
28	Tries to teach your child with a developmental disability how to behave	1	2	3	4	5
29	Takes advantage of your child with a developmental disability	1	2	3	4	5
30	Blames your child with a developmental disability when something goes wrong	1	2	3	4	5
31	Is very competitive against your child with a developmental disability	1	2	3	4	5
32	Resents your child with a developmental disability	1	2	3	4	5

Appendix C

Sibling Inventory of Behavior Revised - Sibling

For each item, read the questionnaire to the participating typically developing sibling, using the name of the affected sibling.

1	2	3	4	5
Never	Seldom	Sometimes	Always	Often

How often are you/do you...

- | | | | | | | |
|-----------------------------------------------|----------------------|---|---|---|---|---|
| 1. Happy when (_____) | does well | 1 | 2 | 3 | 4 | 5 |
| 2. Tease or annoy (_____) | | 1 | 2 | 3 | 4 | 5 |
| 3. Get angry with (_____) | | 1 | 2 | 3 | 4 | 5 |
| 4. Play with (_____) | | 1 | 2 | 3 | 4 | 5 |
| 5. Want (_____) | to succeed (do well) | 1 | 2 | 3 | 4 | 5 |
| 6. Stay away from (_____) | when you can | 1 | 2 | 3 | 4 | 5 |
| 7. Think of things you can do with (_____) | | 1 | 2 | 3 | 4 | 5 |
| 8. Argue with (_____) | | 1 | 2 | 3 | 4 | 5 |
| 9. Have fun at home with (_____) | | 1 | 2 | 3 | 4 | 5 |
| 10. Are ashamed of (_____) | | 1 | 2 | 3 | 4 | 5 |
| 11. Feel bad when things are hard for (_____) | | 1 | 2 | 3 | 4 | 5 |

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

12. Get upset when you have to be with (_____)	1	2	3	4	5
13. Teaches (_____) new things	1	2	3	4	5
14. Help (_____) in a new situation	1	2	3	4	5
15. Treat (_____) as a good friend	1	2	3	4	5
16. Try to avoid being seen with (_____)	1	2	3	4	5
17. Want (_____) to be happy	1	2	3	4	5
18. Make plans that include (_____)	1	2	3	4	5
19. Hurt (_____)’s feelings	1	2	3	4	5
20. Try to comfort (_____) when s/he is unhappy or upset	1	2	3	4	5
21. Share secrets with (_____)	1	2	3	4	5
22. Take care of (_____)	1	2	3	4	5
23. Tattle on (_____)	1	2	3	4	5
24. Are jealous of (_____)	1	2	3	4	5
25. Have physical fights with (_____) (not just for fun)	1	2	3	4	5
26. Nosy about (_____) and try to find things out about him	1	2	3	4	5
27. Try to teach (_____) how to behave	1	2	3	4	5

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

- | | | | | | |
|-----------------------------------------------|---|---|---|---|---|
| 28. Use (_____) to get something you want | 1 | 2 | 3 | 4 | 5 |
| 29. Blames (_____) when something goes wrong | 1 | 2 | 3 | 4 | 5 |
| 30. Competitive with (_____) | 1 | 2 | 3 | 4 | 5 |
| 31. Dislike (_____) | 1 | 2 | 3 | 4 | 5 |
| 32. Embarrassed to be with (_____) | 1 | 2 | 3 | 4 | 5 |

Appendix D

Sibling Relationship Questionnaire Revised - Parent

10

ID # _____

GROUP _____

Sibling Relationship Questionnaire - Revised (Parent) 3/90

This questionnaire was completed by mother/father (circle one)

The phrase "this sibling" refers to _____

Blank lines refer to _____

1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both _____ and this sibling do nice things for each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
2. Who usually gets treated better by mother, _____ or this sibling?	<input type="checkbox"/> This sibling almost always gets treated better <input type="checkbox"/> This sibling often gets treated better <input type="checkbox"/> The children get treated about the same <input type="checkbox"/> _____ often gets treated better <input type="checkbox"/> _____ almost always gets treated better
3. How much does _____ show this sibling how to do things he or she doesn't know how to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
4. How much does this sibling show _____ how to do things he or she doesn't know how to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
5. How much does _____ tell this sibling what to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
6. How much does this sibling tell _____ what to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

7. Who usually gets treated better by father, _____ or this sibling?	<input type="checkbox"/> This sibling almost always gets treated better <input type="checkbox"/> This sibling often gets treated better <input type="checkbox"/> The children get treated about the same <input type="checkbox"/> _____ often gets treated better <input type="checkbox"/> _____ almost always gets treated better
8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do _____ and this sibling care about each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
9. How much do _____ and this sibling go places and do things together?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
10. How much do _____ and this sibling insult and call each other names?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
11. How much do _____ and this sibling like the same things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
12. How much do _____ and this sibling tell each other everything?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
13. Some siblings try to out-do or beat each other at things a lot, while other siblings try to out-do each other a little. How much do _____ and this sibling try to out-do each other at things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
14. How much does _____ admire and respect this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

15. How much does this sibling admire and respect _____?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
16. How much do _____ and this sibling disagree and quarrel with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do _____ and this sibling cooperate with other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
18. Who gets more attention from mother, _____ or this sibling?	<input type="checkbox"/> This sibling almost always gets more attention <input type="checkbox"/> This sibling often gets more attention <input type="checkbox"/> The children get about the same amount of attention <input type="checkbox"/> _____ often gets more attention <input type="checkbox"/> _____ almost always gets more attention
19. How much does _____ help this sibling with things he or she can't do by him or herself?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
20. How much does this sibling help _____ with things he or she can't do by him or herself?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
21. How much does _____ make this sibling do things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
22. How much does this sibling make _____ do things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

<p>23. Who gets more attention from father, _____ or this sibling?</p>	<p><input type="checkbox"/> This sibling almost always gets more attention <input type="checkbox"/> This sibling often gets more attention <input type="checkbox"/> The children get about the same amount of attention <input type="checkbox"/> _____ often gets more attention <input type="checkbox"/> _____ almost always gets more attention</p>
<p>24. How much do _____ and this sibling love each other?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do _____ and this sibling play around and have fun with each other?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>26. How much are _____ and this sibling mean to each other?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>27. How much do _____ and this sibling have in common?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>28. How much do _____ and this sibling share secrets and private feelings?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>29. How much do _____ and this sibling compete with each other?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
<p>30. How much does _____ look up to and feel proud of this sibling?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>

31. How much does this sibling look up to and feel proud of _____?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
32. How much do _____ and this sibling get mad at and get in arguments with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
33. How much do both _____ and this sibling share with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
34. Who does mother usually favor, _____ or this sibling?	<input type="checkbox"/> This sibling almost always is favored <input type="checkbox"/> This sibling often is favored <input type="checkbox"/> Neither of the children is favored <input type="checkbox"/> _____ is often favored <input type="checkbox"/> _____ is almost always favored
35. How much does _____ teach this sibling things that he or she doesn't know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
36. How much does this sibling teach _____ things that he or she doesn't know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
37. How much does _____ order this sibling around?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
38. How much does this sibling order _____ around?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

39. Who does father usually favor, _____ or this sibling?	<input type="checkbox"/> This sibling almost always is favored <input type="checkbox"/> This sibling is often favored <input type="checkbox"/> Neither of the children is favored <input type="checkbox"/> _____ often is favored <input type="checkbox"/> _____ almost always is favored
40. How much is there a strong feeling of affection (love) between _____ and this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
41. Some kids spend lots of time with their siblings, while others don't spend so much. How much free time do _____ and this sibling spend together?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
42. How much do _____ and this sibling bug and pick on each other in mean ways?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
43. How much are _____ and this sibling alike?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
44. How much do _____ and this sibling tell each other things they don't want other people to know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
45. How much do _____ and this sibling try to do things better than each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
46. How much does _____ think highly of this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
47. How much does this sibling think highly of _____ ?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

<p>48. How much do _____ and this sibling argue with each other?</p>	<p><input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH</p>
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Appendix E

Sibling Relationship Questionnaire Revised - Parent

4

ID # _____

GROUP _____

Sibling Relationship Questionnaire - Revised (Child) 3/90

My name is _____ (completed by)

The phrase "this sibling" refers to _____ (completed about)

1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both you and this sibling do nice things for each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
2. Who usually gets treated better by your mother, you or this sibling?	<input type="checkbox"/> My sibling almost always gets treated better <input type="checkbox"/> My sibling often gets treated better <input type="checkbox"/> We get treated about the same <input type="checkbox"/> I often get treated better <input type="checkbox"/> I almost always get treated better
3. How much do you show this sibling how to do things he or she doesn't know how to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
4. How much does this sibling show you how to do things you don't know how to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
5. How much do you tell this sibling what to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
6. How much does this sibling tell you what to do?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

7. Who usually gets treated better by your father, you or this sibling?	<input type="checkbox"/> My sibling almost always gets treated better <input type="checkbox"/> My sibling often gets treated better <input type="checkbox"/> We get treated about the same <input type="checkbox"/> I often get treated better <input type="checkbox"/> I almost always get treated better
8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do you and this sibling care about each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
9. How much do you and this sibling go places and do things together?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
10. How much do you and this sibling insult and call each other names?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
11. How much do you and this sibling like the same things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
12. How much do you and this sibling tell each other everything?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
13. Some siblings try to out-do or beat each other at things a lot, while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
14. How much do you admire and respect this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

15. How much does this sibling admire and respect you?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
16. How much do you and this sibling disagree and quarrel with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
18. Who gets more attention from your mother, you or this sibling?	<input type="checkbox"/> My sibling almost always gets more attention <input type="checkbox"/> My sibling often gets more attention <input type="checkbox"/> We get about the same amount of attention <input type="checkbox"/> I often get more attention <input type="checkbox"/> I almost always get more attention
19. How much do you help this sibling with things he or she can't do by him or herself?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
20. How much does this sibling help you with things you can't do by yourself?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
21. How much do you make this sibling do things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
22. How much does this sibling make you do things?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

23. Who gets more attention from your father, you or this sibling?	<input type="checkbox"/> My sibling almost always gets more attention <input type="checkbox"/> My sibling often gets more attention <input type="checkbox"/> We get about the same amount of attention <input type="checkbox"/> I often get more attention <input type="checkbox"/> I almost always get more attention
24. How much do you and this sibling love each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
26. How much are you and this sibling mean to each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
27. How much do you and this sibling have in common?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
28. How much do you and this sibling share secrets and private feelings?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
29. How much do you and this sibling compete with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
30. How much do you look up to and feel proud of this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

31. How much does this sibling look up to and feel proud of you?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
32. How much do you and this sibling get mad at and get in arguments with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
33. How much do both you and your sibling share with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
34. Who does your mother usually favor, you or this sibling?	<input type="checkbox"/> My sibling almost always is favored <input type="checkbox"/> My sibling is often favored <input type="checkbox"/> Neither of us is favored <input type="checkbox"/> I am often favored <input type="checkbox"/> I am almost always favored
35. How much do you teach this sibling things that he or she doesn't know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
36. How much does this sibling teach you things that you don't know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
37. How much do you order this sibling around?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
38. How much does this sibling order you around?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
39. Who does your father usually favor, you or this sibling?	<input type="checkbox"/> My sibling almost always is favored <input type="checkbox"/> My sibling is often favored <input type="checkbox"/> Neither of us is favored <input type="checkbox"/> I am often favored <input type="checkbox"/> I am almost always favored

40. How much is there a strong feeling of affection (love) between you and this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
41. Some kids spend lots of time with their siblings, while others don't spend so much. How much free time do you and this sibling spend together?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
42. How much do you and this sibling bug and pick on each other in mean ways?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
43. How much are you and this sibling alike?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
44. How much do you and this sibling tell each other things you don't want other people to know?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
45. How much do you and this sibling try to do things better than each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
46. How much do you think highly of this sibling?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
47. How much does this sibling think highly of you?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH
48. How much do you and this sibling argue with each other?	<input type="checkbox"/> Hardly at all <input type="checkbox"/> Not too much <input type="checkbox"/> Somewhat <input type="checkbox"/> Very much <input type="checkbox"/> EXTREMELY MUCH

Appendix F

Coding Guide for Observed Sibling Interactions

STEP 1: code communicative events

Using the definitions below, code each *communicative event* on the part of sibling and child with DS, directed to each other. Ignore communicative behavior directed to adults in the vicinity.

Videos should last for 5 min.

Code the entire video recording for a dyad one time. Code it a second time on another day. Then compare the two codings, rectifying discrepancies and create a final coding for the dyad that you copy to the data sheet for STEP 2.

Communicative behavior you may see includes:

Movement: Includes both gestures and/or physical movement.

- Gesture: fine and gross motor body movements, eye behaviors (e.g., gaze, wink), postures (e.g., point, show, give, raise eyebrows, grimace, nod, shake head), and physical prompting (from sibling, not from adult)
- Physical movement: taking piece, moving game piece, picking up piece and taking turn, bodily action not meeting criteria for gesture, but that accompanies other forms of communication (e.g., eye gaze) or is in clear response to communication from partner (e.g., taking card in response to partner's "your turn" so taking card indicates continuation of interaction rather than breakdown)

Verbal: speech including sounds, single words and multiword phrases.

Prompted: if adult provides specific direction that, within 3 seconds, results in the child's behavior toward partner (e.g., adult tells sibling to take target child to another area of room; adult hands target child a piece to help him take his turn in response to the sibling's request for action, "Your turn."). Do not code prompts to take turns if no other topography accompanies it

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STEP 1

[illegible]

STEP 2: code communicative events as responses or initiations

Using the definitions below, code each *communicative event* from Step 1 on the part of sibling and target child, directed to each other.

If one child keeps communicating, start a new event if clearly a different topic or function or if 3 seconds elapses between one form/forms and another (then it's 2 communicative events).

Code the entire video recording for a dyad one time. Code it a second time on another day. Then compare the two codings, rectifying discrepancies and create a final coding for the dyad.

1. Enter video clip title/code, your initials, date of coding, and page number of coding, and whether 1st, 2nd, or final coding on the top of the data sheet.
2. Make sure the start time stamp for each communicative event is listed in the left hand column
3. **Record:**

Initiation/Response:

Code each communicative event as an initiation or a response.

Initiation = behavior clearly directed to other child (e.g., involving eye contact, tapping, using name, etc.) not preceded in 3 seconds by behavior of the other child

Response = behavior that occurs specific to and within 3 seconds of a preceding behavior from another child.

Subject: write either "sib" for sibling or the first letter of the name of the child with autism to indicate who is engaged in the communicative act being coded

Stop time: Record the stop time when the series of responses has ended (i.e., the series of responses has ended when a response is followed up by no communicative event within 3 seconds). The stop time is the time at end of the last response.

STEP 3: Code communicative events as prosocial or agonistic

Using the definitions below, code each *communicative event* from Step 1 on the part of sibling and target child, directed to each other.

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Prosocial communicative event:

<u>CODE</u>	<u>DEFINITION</u>
Give/Share Object	Gives an object spontaneously or shares an object with which the other child is already playing (parallel play only)
Cooperate/help	Explanations and physical aid
Request	Asking for something (e.g. a toy, help) in a polite manner, low tone of voice, often accompanied by positive facial expression (e.g. by calling siblings name) and for information (e.g. "What are you doing?").
Praise/approval	Verbal statements of approval or admiration of sibling or his/her behaviour
Comfort/reassurance	Verbal or physical reassurance when the sibling is in some way distressed
Physical affection	Positive physical contact, specifically hug, kiss, hold hands, pat
Laugh/smile	Facial expression of laughter or smiling directed to the sibling, not accompanied by any other behavior
Approach	Moving to within .5 m of sibling with no evidence of agonistic intent and not accompanied by any other behavior
Play initiation	By statement, question or action the child indicates he/she wants to begin a game, e.g. "let's play marbles." Only cooperative play coded here
Rough and tumble	Child initiates prosocial physical play including chasing, wrestling, tickling.
Clowning	Playful teasing or acting in a silly manner designed to elicit laughter, e.g. child pulls funny faces or says something silly such as "I know where it is, in your ear"
Establishing rules/turn taking	Statement establishing a mode of conduct within a game, e.g. "This is home and when you're here you're safe", or a statement to negotiate turns, (e.g. "I'll go first, then it's your turn").
Command with reason	An order or command with explanation, e.g. "stop banging because it's hurting my ears" Not delivered in a loud tone of voice or accompanied by threatening facial expression or gestures

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

Communicative Comment	Verbal statements not included above, e.g. "you are drawing a house." Greetings. Not accompanied by negative affect.
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Agonistic communicative event:

<u>CODE</u>	<u>DEFINITION</u>
Physical aggression	Assertive physical contact. Specifically; hit, push, shove, kick, bite, pinch, pull hair.
Object struggle	A fight over an object.
Command	An order or demand stated with authority in a loud tone of voice; may be accompanied by threatening facial expression or gestures
Insult/disapprove	Teasing, name calling, unfavorable judgements.
Threat	Statement of intent to harm, or take toys away.
Tattle-tell	Telling mother about the other sibling's "wrong-doings"
Territorial Claim	A statement indicating sole possession of an object or position, e.g. "don't touch these, they're all mine"
Repeats parent's claim	Restates or indicated commands made by parents, e.g. "Mummy said not to do that".
Competitive statement	Statements of superiority or comparison, e.g. "I can finish this faster than you".
Bribe/bargain	Bribing, bargaining or any offers to trade in order to elicit desired behaviours, e.g. "I'll give you that crayon if you'll give me this one"
Physical tease	Actions sustained or repeated with the deliberate intention of annoying the other child, e.g. child A blocks the door so child B cannot leave.

Any behavior not captured above will not be coded.

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STEPS 2 and 3:

Video Clip:			Coder Initials:		Page:		
1st	2nd	Final	Date:				
Start time (from Step 1)	Response (R) or Initiation (I)	Subject	Stop time	Affect	Prosocial (P) or Agonistic (A)	P or A Code	

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

Curriculum Vitae

Name: Jill Miko

PROFESSIONAL EXPERIENCE

Counselling Internship
April 2018-present
Supportive Care, St. Joseph's Hospice, London, ON

Clinical Coordinator
Maritime Newborn Screening Program
March 2015 – March 2017
Department of Laboratory and Pathology Services, IWK Health Centre, Halifax, NS

Genetic Counsellor
February 2014 –October 2014
Windsor Regional Cancer Centre, Windsor Regional Hospital, Windsor, ON

Learning Skills Counsellor
August 2011-September 2013
Student Development Centre, University of Western Ontario, London, ON

Genetic Counsellor
April 2010 – May 2011
Edmonton Medical Genetics Clinic, Stollery Children's Hospital, Edmonton, AB

EDUCATION

Master of Arts in Counselling Psychology
September 2017 – Present, Graduating in April 2019
Western University, London, ON

Master of Science in Genetic Counselling
September 2007 – May 2009
University of British Columbia, Vancouver, BC

Bachelor of Science with Specialization in Psychology, With Distinction
September 2002 – May 2007
University of Alberta, Edmonton, AB

PAST RESEARCH EXPERIENCE

Directed Studies Research Project for the Master of Science in Genetic Counselling Program
September 2007 – May 2009

SOCIAL SKILLS SUPPORT PROGRAM AND SIBLING RELATIONSHIP

University of British Columbia, Vancouver, BC

- Miko, J., Bruyere, H., LaPointe, M., Bamforth, S., Koehn, D. *Pregnancy Decisions and Clinical Outcome Following Prenatal Diagnosis of De Novo Chromosome Rearrangements*

HONOURS AND AWARDS

MA Entrance Scholarship

Graduate Student Assistantship

September 2017 – Present

Western University, London, ON

Natural Science and Engineering Research Council of Canada (NSERC)

Undergraduate Student Research Award

May 2005 – August 2005

University of Alberta, Edmonton, AB